Testimony submitted February 26, 2013
Connecticut State Legislature, Public Health Committee
Submitted by:
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Dear Members of the Committee,

I am writing to urge your support for our proposal to amend Senate Bill 129, which is currently before your committee, with language to reopen the Southbury Training School ("STS") to new admissions. Senate Bill 129 calls for preventing the closure of the Hartford Regional Center, an ICF-level facility.

Currently, Connecticut is on a path to close all of the state operated facilities and move all of the services for its intellectually disabled and developmentally (ID/DD) disabled citizens to the private sector. While private facilities do offer good services and are appropriate to many people in the ID/DD community, I do not feel that one size fits all in this system. I believe the state operated facilities offer a safety net that is needed to cover the gaps inherent in a private, forprofit system. Regardless of their standing as non-profits, all private run institutions must at least break even, or else they go out of business. State run facilities are only protection that the most vulnerable, most difficult patients have within the system. They must not be allowed to close. Ending the availability of state run services amounts to gambling with the lives and well-being of these people. Once these facilities are closed, it will be almost impossible to bring them back.

STS is a crucial part of Connecticut's system of care for the intellectually and developmentally disabled. STS is a state-run Intermediate Care Facility that meets strict federal standards. In addition to providing comprehensive services to the people who live there, STS provides dental and other services to more than 500 community-based clients of the Department of Developmental Services. Reopening the doors at STS will both revitalize the facility and benefit many more people in the surrounding community. It would also ease the strain of the current waiting lists, by moving some ID/DD clients to this community and making more room in the private sector. Many families of people with severe disabilities would be happy to be able to place their loved ones in the care of the community of STS.

My brother Tom is 56 years old. He has lived at Southbury Training School for the last forty years. Tom is developmentally disabled, what was once referred to as profoundly retarded, as well as suffering from severe autism and bi-polar disorder. He also suffers from physical disorders, including middle stage Parkinson's Disease and a loss of vision through an irreparably detached retina and a cataract in the other eye. He tends to swallow his food without chewing, so all of his food must be ground or pureed so he won't choke on it. Tom has PICA issues, which means that he will pick up small items and try to swallow them. This behavior resulted in a blockage of one intestine and perforation of the other and extensive surgery several years ago. Tom does not speak, and cannot brush his teeth or go to the toilet by himself. He also stumbles

when he walks and requires that someone hold a large belt around his waist whenever he seeks to do so. Tom requires that someone be with him during all his waking hours.

When he was four years old, my parents determined that they were unable to provide the level of attention he needed at home. They enrolled him in a series of schools and institutions over the years, trying to find facilities that were appropriate to his needs as his body developed though childhood and adolescence and into adulthood. As I stated above, for the last forty years, Tom has lived at STS. This is his home. This is his community. At Southbury, Tom has a level of comfort and familiarity that are vital to his well-being.

Like my brother Tom, most of the residents of STS are severely disabled, suffering from intellectual, physical, and medical disabilities. STS offers an array of services that are crucial to the well-being of this population. They include 24/7 on-site medical staff, a health care unit that enables individuals to receive care that would otherwise be available only in a hospital or nursing home, staff psychiatrists who are familiar with the history of each resident, an experienced staff with minimal turnover and a dental clinic. More important to this committee, there are many others in the state of Connecticut who would benefit from having a home or being able to partake in the services offered by STS.

Due to both a court order which is no longer in effect, and a bill passed by the Connecticut Legislature without the input of STS families or guardians, new admissions to STS have been blocked since 1986. As a result, the fixed costs of operating STS have been spread since the 1980s over a steadily shrinking base of residents, and the cost of care per resident has steadily risen. This has periodically fueled an argument from opponents of the facility that it should be closed.

Allowing new admissions to STS would accomplish the following:

- -- New admissions would result in a lowered cost of care per resident at the facility and help make it financially viable.
- -- New admissions would shorten or possibly eliminate a growing waiting list for residential care and services for intellectually disabled people throughout the state.
- -- New admissions would allow STS to continue and possibly expand its role as a resource for dental and medical care for community-based clients of DDS.
- -- New admissions would ensure that the State of Connecticut fulfills its obligation to provide a safety net for its most vulnerable citizens and their families.

I believe it is vital to the ID/DD community and to the integrity of the State of Connecticut that you vote to reverse the direction taken in recent years, and vote to prevent the closure of the Hartford Regional Center and to reopen STS to new admissions. Thank you for this opportunity to address my concerns.

Hugo Dwyer